



National MPS Society Journey Assistance Program - 2024 Eligibility and Guidelines

Journey Assistance Program – to help your journey with MPS or ML.

The National MPS Society offers grants to help purchase exceptional items needed during the MPS/ML journey. Items requested shall be for exceptional items that have the potential to make your life easier or more enjoyable. These exceptional items typically have limited funding options and are often out-of-pocket expenses for families.

Journey Grants will be awarded for 40% of the total purchase price and will not exceed \$500 per individual with MPS or ML.

Eligibility Requirements:

- Current U.S. resident with an active National MPS Society membership, updated annually
- Parents of a child with MPS or ML (applying on behalf of an item for the individual diagnosed) or adult with MPS or ML
- No age limits
- Application should be submitted before purchasing item

Items eligible for funding (but not limited to):

- iPads, other tablets, and Kindles
- Laptop/Computer Grants – (students in High School or post High School education)
- High School/College class ring
- Technology Aids (Livescribe Smart Pens, software programs, apps, etc.)
- Wagons for transporting children
- Open to other requests not routinely covered by insurance or other means- check with us to verify eligible items

Items not eligible for funding (but not limited to):

- Cell phones
- Items with recurring payments
- Durable medical goods
- Live animals
- Therapy services, nursing care, or other programs

Process:

- 1) Only parents/guardians of an individual with MPS or ML (applying on behalf of the individual) or an adult with MPS or ML who reside in the United States and have an active membership, updated annually, are eligible to apply.
- 2) Strictest confidentiality regarding application, names and funding will be maintained by the society.
- 3) Funds will be made available only for non-recurring, exceptional and extraordinary costs. Ongoing expenses incurred by members and durable medical goods are not covered under this assistance program.
- 4) The applicant should be willing to donate the item to another Society member when it is no longer needed.
- 5) Application for assistance should be made in advance of a cost being incurred. Special consideration may or may not be made if the cost has been incurred. Award will be granted once the receipt showing total purchase prices has been submitted.
- 6) Examples of potentially eligible costs are computers, tablets, class rings, and technical communication devices. If you have questions about an item's eligibility, please let us know.
- 7) Grants for Journey may be requested up to a maximum of **\$500** per affected individual, per 12-month period, dependent on available funds and the Committee's decision. Each Journey Grant will be for 40% of the total purchase price, not to exceed \$500. Multiple grants can be submitted, not to exceed \$500 funded in a 12- month period. Multiple grants for one family membership may be awarded only for single user items.
- 8) A minimum of 60% of the total cost of the requested item must be funded by the applicant or by other sources.
- 9) All required documentation must accompany the Journey application form prior to application being reviewed. Applications will be reviewed by the committee upon receipt of all documentation, and the Society's office will notify the applicant of the funding decision.
- 10) The Society will notify the applicant indicating whether the application has been approved or denied and the amount of funding granted, if any.
- 12) Funding will be reimbursed directly to the applicant upon the Society receiving an original or photocopy of the receipt.

Application Review

- 1) Application will be reviewed once all required documentation is received.
- 2) The Family Support Committee will review a summarized version of the application and determine funding status.
- 3) Reimbursement will be made to the applicant if selected for funding. This will require the applicant to supply a paid receipt for the requested item.
- 4) The Family Support Committee's interpretation of the regulations outlining the Journey Assistance Program and any decisions made by the Committee are binding. Appeals can be made to the Board of Directors in writing within 60 days of denial. The appeal will be reviewed at the next board meeting.
- 5) In the event that funds budgeted for the current year are depleted, the Family Support Committee will not review additional applications that year. Applications will be accepted and reviewed after January 1.
- 6) If funding is approved, applicant must submit receipts and accept funds within 90 days. Items not funded within 90 days of approval will require resubmission.